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Voices From the Community

Guest Editorial by Yvonne Atwell, Policy Analyst

Atlantic Centre of Excellence for Women's Health

THE EDITORS OF THE *Centres of Excellence for Women's Health Research Bulletin* have invited me to comment on the articles in this issue devoted to capturing "Voices from the Community." The research featured here explores the experiences of women who have been marginalized in and by society, including immigrant women, Aboriginal women, female sex trade workers, women living in poverty, lesbians, women in conflict with the law and women who have been subject to violence and other forms of abuse. These articles detail the numerous and overwhelming barriers to health and wellness faced by disadvantaged women—whether they are trying to navigate through the legal system, the health care system, social services or the tasks of daily living.

The studies supported by the Centres of Excellence for Women's Health represent a modest but vital contribution to the enormous amount of work that remains to be done to improve the health and well being of vulnerable and marginalized women in our society. By giving voice to women who have typically been silenced, these articles confirm that there is a crisis in health research, policy and practice. Although hundreds of thousands of women in this country are living in conditions of profound personal, social and economic insecurity, they continue to be ignored by many researchers and research funding agencies, by many of those who formulate and implement municipal, provincial and federal policies, and by many of those who deliver housing, income, social and health care services. By focusing on specific populations of women, by examining health through a comparative "gender lens," this research also confirms the differential impact of economic, social, political and cultural factors on diverse groups of women and between women and men. For example, Lynn McIntyre and her colleagues in Nova Scotia interviewed Mi'kmaq youth living on reserve and found that young

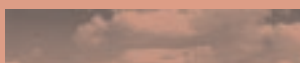
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RECYCLED LOGO UNION BUG

(WPG SUN: PLS PLACE LOGOS)

■ Women need adequate resources and political will committed to the goal of creating a just and caring society.

c o n t ' d

women were twice as likely as young men to report feeling sad, depressed or extremely stressed. Abuse, lack of education, poverty and discrimination all weigh more often and more heavily on women than on men and compound the disadvantages experienced by specific groups of women. At the same time these studies stress the imperative of moving from research to action. For example, we have long known that immigrant women are at high risk of depressive conditions, including Post Traumatic Stress Disorder (PTSD). Many have endured traumatic experiences in their countries of origin and many are further stressed by immigration itself. The study from the Prairie Centre confirms that PTSD is exacerbated by the “day-to-day struggles of adapting to a new environment, often without language skills, community or family support.” Yet many of our policies and practices remain insensitive to the needs of new residents and aspiring citizens of Canada. Studies conducted with Aboriginal women, women of colour and women living in poverty or abusive situations lead to similar conclusions. These women need a more equitable and inclusive society. They need to know that leaders in Canada will endorse new policies and practices that ensure fair and appropriate care for all. They need to know that service providers will respect cultural diversity as well as social and economic differences. They need adequate resources and political will committed to the goal of creating a just and caring society.

Some of the research highlighted in this issue is decidedly action-oriented and empowering. Wanda Thomas Bernard, who has conducted health research studies with African Nova Scotian women, concludes “action means sharing individual and collective power in health research and using power and privilege to effect change.” Frances Shaver’s research with sex trade workers likewise emphasizes the importance of “giving back to the community” and empowering disenfranchised women. But some studies still shy away from explicitly addressing the effects of systemic

discrimination. Annette Browne and Jo-Anne Fiske are among the few investigators who grapple openly with the implications of racism, sexism, and other forms of prejudice in our society. They acknowledge that it is the “interests of dominant groups [that] float to the surface, as does the language that promotes their interests.”

Moreover, the research highlighted here focuses on the deplorable conditions that characterize the lives of many disadvantaged women in Canada, but largely ignores positive dimensions and effective coping strategies. One possible interpretation is that an essentially white, middle-class, urban standard of wellness and health is in place. Lives that do not resemble this standard then appear shabby, unwholesome and thoroughly unpleasant, rather than unnecessarily difficult. The Centres of Excellence for Women’s Health, increasingly mindful of the need for more and deeper analysis of the impact of systemic discrimination on women’s health, have begun investing in research and policy activity about relevant themes, including “racism as a determinant of health.” We eagerly look forward to the fruits of this groundbreaking work.

In the final analysis, the research supported by the Centres of Excellence underscores our responsibility to vulnerable and marginalized women and men—both as researchers and as citizens of civil society. When people welcome us into their lives in the name of research, we must be ready to respond with information, skills and opportunities to effect genuine and lasting changes. When we go to the polls, when we meet with politicians and policy makers, we must be prepared to advocate for a more equitable and inclusive society.



The Discredited Medical Subject in Health Policy and Practice: Carrier First Nation Women in Northern British Columbia

Annette Browne, Assistant Professor, School of Nursing, University of British Columbia, and Jo-Anne Fiske, Associate Professor, First Nations Studies and Women's/Gender Studies, University of Northern British Columbia, British Columbia Centre of Excellence for Women's Health. The authors spoke to Leslie Grant Timmins of the *Research Bulletin*.

Research Bulletin: In the first phase of your research study you looked at encounters between Carrier First Nation women and health service providers in the northern interior of British Columbia. Your report described the unequal power relations in these encounters and their negative impact on the women. What are you doing in the second phase of your study?

Jo-Anne Fiske: We took another look at the women's narratives, applying certain theoretical perspectives. Embedded in the women's interviews we found explicit and implicit recommendations for policy changes. We analyzed provincial and federal health policy reform and found that, very frequently, First Nations women's participation in policy reform does not bring about the results they desire.

Annette Browne: Women we'd interviewed had described the various ways in which health providers unwittingly conveyed dismissive attitudes—making women feel as if they were essentially invalid medical subjects. The processes of health policy reform and consultation, and existing health policy, also tend to construct Aboriginal women as “incredible” medical subjects.

RB: What does “incredible” mean?

AB: Discredited, non-credible. I'm thinking of the local clinic's policy of imposing a \$20 penalty for missed or late appointments. That kind of policy may be necessary to the financial viability of the clinic, but it ends up penalizing and constructing Aboriginal women as incompetent. The policy positions the women as “incredible” by reinforcing this

notion, this popular notion, of Aboriginal women as irresponsible because they are not able to meet the expectations of the clinic operations.

JF: The women don't have \$20 to pay the penalty, they don't have cars. The 20 kilometre trip from the reserve to the clinic is not easy to arrange. So they leave the clinic and walk across the parking lot to emergency care at the hospital. This is much more expensive to the health care system, but they have no alternative. So what you have as a result of this policy is a greater emphasis on a negative image of women because they failed to treat the clinic properly. The policy creates conditions that reinforce stereotypes, difference, and social distance.

RB: Are you saying that health care reform and consultation does the same thing?

AB: Within health policy discourses of citizenship—for example, the appeal for citizens to respond to health care reform through the Romanow Commission, and the Royal Commission on Aboriginal People (1996), which was a five-year intensive consultation process—there's a paradox. There's an appeal to “citizenship,” to rights and obligations to direct health policy through participation in governance. But what actually happens is that Aboriginal people are undermined by these discourses and positioned as lacking power.

RB: Lacking power in what way?

JF: When you start the process, certain interests of dominant groups float to the surface, as does the language that promotes their interests, sometimes not consciously. For example,

during our study, Aboriginal women told us they wanted to have more advocates in the local and regional hospitals—First Nations liaison workers—not only in the acute care sector, but in primary care and community care as well.

AB: The women wanted these liaison workers because of dismissive attitudes that are often conveyed towards them in these sectors. Through their attitudes, though often unintentional, workers disparaged the women's role as responsible mothers, showed resentment towards them as undeserving recipients of "free" government aid, and showed a lack of sensitivity or understanding of their behaviour (shyness, for example) during medical exams that evoked past sexual abuse they'd experienced in residential schools.

The local health clinic has no First Nations workers at all. And there is still only one such liaison worker in the regional hospital. The women wanted more liaison people to be public advocates, to speak to things that need to be changed.

JF: Requests for policy changes through the presence of Aboriginal workers can be positive, but not necessarily so. All too often policy makers take up these recommendations, but translate and reframe them in a manner that supports the existing power structures. This is what appears to have happened with the liaison position: the women's recommendation for advocacy—a way to make change and address structural problems—is translated into, for example, a need for more social workers, who will give more directives about how *the women* should change their lives. It's another gatekeeper approach to the women's "lifestyle." The very terms the women wanted to challenge are used to frame the policy. And the power structure stays the same.

AB: By identifying the invalidating encounters that Aboriginal women experienced in a health clinic, our report on the first phase of our research added fuel to the argument for

additional hours and funding to expand the Native liaison worker position at the hospital. The findings of our report have been taken up by the Medical Officer of Health, but to date there's still only one Aboriginal liaison worker.

RB: You recommend "cultural safety" over "cultural sensitivity" training of health care practitioners to address problems at the service level. What's the difference between "sensitivity" and "safety"?

AB: There has been a movement to make both health policy and health services more culturally sensitive. These policies are founded in concepts of cultural difference: I learn about your cultural differences and can therefore understand your "different" behaviour. This stigmatizes. It also directs responsibility for "cultural differences"—which may be structurally mediated—back onto individuals and away from relations and structures of power.

JF: Cultural safety looks beyond cultural differences. It is concerned with changing attitudes, but moves beyond superficial understanding to place responsibility on members of the dominant society to look at the power and privileges of their own social position. That is, in order to offer professional services that are safe, the professional needs to gain an awareness of the political and historical forces shaping the dynamics of health care interactions with Aboriginal people. So, for example, practitioners can reflect on the *structures* they're working in instead of trying to account for or blame an individual's behaviour.

AB: It's a relatively new concept. It originated from Maori nurse-leaders in New Zealand who were involved in health reform. Now all nurses there have to study the colonial history and are tested on it. This is different from learning a superficial etiquette about culture. It's very effective at a micro level, in everyday encounters between patients and

■ The dominant culture ends up being the driving force in health care and health reform.

■ In order to offer services that are safe, the health care professional needs to gain an awareness of the political and historical forces shaping the dynamics of health care interactions with Aboriginal people.

health care providers. How it can be mobilized at a macro policy level has to be explored in more depth.

JF: What we're trying to argue in the report we're preparing now is that some groups' perspectives and knowledge are privileged over others and that the dominant culture ends up being the driving force in health care and health reform.

RB: Is awareness about privilege and power really sufficient to bring about significant change?

AB: No, but awareness is an improvement. And we're not trying to blame individual providers and fall into the trap of labelling individuals as racist. This also takes the focus off power structures. Let's talk about racism as embedded in the fabric of society.

RB: How can culturally safe practices change the discrediting attitudes in the health clinic?

AB: Clinic practices and policies that convey respect for Aboriginal women's primary roles as gate-keepers to the health care system and community leaders. That take into account poverty and the social and historical forces behind poverty. And, just as importantly, practices and policies that ensure the *meaningful* participation of Aboriginal women in decision making at the local health level.

JF: At national and regional policy levels, instead of continuing to focus on inviting Aboriginal people to make health policy more "culturally sensitive," ways can be found to address the underlying social determinants of health. For example, when we look at policy on Aboriginal health, we see a highlighting of certain illnesses and a link to "lifestyle." HIV, substance use, for example. This tagging reinforces and

marks Aboriginal women as discredited medical subjects.

AB: And ignores the underlying causes of high rates of these illnesses and problems. There's a lack of focus on the social determinants such as economic marginalization, welfare colonialism, extreme rates of poverty among women and kids on and off reserve, and regional underdevelopment that have a greater impact on health status.

RB: Aboriginal people in Canada have a high rate of diabetes. How does diabetes fit into the construction of illness and "lifestyle"?

AB: It can work both ways: sometimes it's constructed as a "neutral" disease and sometimes as caused by irresponsibility. But in the latter case you have to ask, what about the diets of people who are economically disadvantaged?

JF: Health policy embraces a very strong North American belief in illness as a matter of lifestyle. If it's lifestyle, then it's an easy fix. This has an appeal at every level of health administration. "Stop eating X." But policy does not analyse *why* certain foods are available and others not. And there are other disabling diseases that are not marked as part of the "epidemics of lifestyle," such as arthritis, that may receive less attention.

AB: What we're seeing and trying to make explicit is that there is an ongoing ideology of individualism that has tremendous impact on Aboriginal people's health and the sorts of solutions that are offered. At the regional health authority level, if you have HIV or a problem with substance use, getting "soft" money, short-term project money, into your community is seen as a solution. Launch a counseling program, for example, as if a three-week program can solve the problem. On paper it looks like the regional health

authority is sending lots of money into Aboriginal communities, but that is misleading. It's really a very small amount of money for very big community issues, spread thinly over a large territory.

AB: When health policy and health care practices construct Aboriginal women as responsible for their illnesses, as "in/credible," discredited subjects in health services, they create a significant barrier to women's health.

JF: The struggle to get outside the colonial legacy and to achieve what you desire through policy reforms is immense. There is an ever present danger of recreating the very power structures that led to the problems in the first place.

The first phase study report, *First Nations Women's Encounters with Mainstream Health Care Services and Systems* (2000), can be downloaded at www.bccewh.bc.ca/Pages/pubspdf.htm or to order a copy contact:



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FIRST NATIONS WOMEN

A Gender Analysis of the Stress Experience of Young Mi'kmaq Women

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In 1997 the Mi'kmaq Health Research Group, made up of health coordinators of three First Nations organizations and academics from Dalhousie University, conducted the Mi'kmaq Health Survey.¹ The single most arresting finding of this study was the stress experience of young females living on reserve. Thirty percent of Mi'kmaq female youth compared to seven percent of Mi'kmaq male youth said they were "quite a bit or extremely stressed." Feeling "sad or depressed for two weeks or more" was selected by 47% of the female youth compared to 21% of male youth. And male Mi'kmaq youth were much more likely to report "I like the way I am" (84%) than were female youth (57%).

The findings of the Health Survey, our first research undertaking, led to our study of adolescent Mi'kmaq women

(12 to 18 years old). *An Exploration of the Stress Experience of Mi'kmaq On-reserve Female Youth in Nova Scotia* (2001) examines physical stressors (e.g., being overweight), mental stressors (e.g., depression, self-esteem, and emotional health) and stressors related to social relationships.

The overall goal of this study was to identify policy and programs that might be effective in reducing the negative stress of young Mi'kmaq women. A second goal was to develop research expertise in First Nations organizations and communities. To capture gender differences and similarities, Mi'kmaq females' stress experiences were compared to those of male youth on reserve. The perspectives of professionals working in youth services were also sought and compared to those of the male and female youth groups. An all-female,

■ Young Mi'kmaq women left school because of pregnancy, young men left because of frustration doing school work.

on-reserve Youth Advisory Group reviewed the research process, advised us on the content of interviews, and contributed to a description of stressors for their peers.

Literature Review

To facilitate an understanding of the stress experiences of female Mi'kmaq youth, it is useful to begin with the historical background. The Royal Commission on Aboriginal Peoples (1996) stated that "Many Aboriginal people are suffering not only from specific diseases and social conditions but also from a depression of spirit resulting from 200 or more years of damage to their cultures, languages, identities and self-respect."² Aboriginal peoples suffered from diseases brought by the European population as well as "traumatic social practices"³ that were part of colonization. The aftermath of the residential schools experience and other government policies and practices have resulted in a socio-health trauma that continues to today, with many inequities still evident in Aboriginal people's health status and access to health services. Yet there are some signs of change: secondary and post-secondary school graduation rates are much improved over the pattern of two or three decades ago, although still behind the Canadian average, and First Nations are taking advantage of treaty and Aboriginal rights provisions to obtain renewed access to resources, an expanded landbase, and funds for economic investment. Aboriginal peoples are gradually regaining control over conditions that affect their health and over health policies, and new data on Aboriginal health are becoming available.

The stress experience of Mi'kmaq women is shaped in part by historical, socio-economic and health conditions, but also by gender-based differences and by prospects for their children. A pattern of giving birth at a younger age than the general population, a shift in family structure resulting in

more single parent families, higher levels of child mortality, higher levels of poverty than Aboriginal men, and a high level of violence against women are key health indicators. In order to deepen our understanding of what lies behind the stress experience of young Mi'kmaq women today, we applied a gender equity analysis to a review of published literature. In the studies we reviewed about depression, we found that the incidence among Canada's young female population is significantly higher than for young males.⁴ With respect to racial/ethnic differences, Roberts and colleagues found that while it appears that these differences in depression are present, it is actually the socio-economic status of the group that encourages or discourages the presence of depression.⁵ Aboriginal youth were found to have one of the highest rates of depression because they live in the lowest socio-economic conditions compared to other groups. Overall, the highest prevalence of depression was found among Aboriginal females due in part to their decrepit living conditions.⁶

Other literature suggests that learning difficulties are a significant health problem for Aboriginal youth and contribute to Aboriginal children's higher rates of school-leaving.⁷ A factor that may contribute to poor school performance may stem from teachers' and others' misunderstanding of cultural differences.⁸

Focus Groups and Interviews

We conducted 21 semi-structured individual interviews and 8 focus group discussions with female Mi'kmaq youth. In order to provide a basis for gender contrast, five individual interviews and two focus groups with male youth living on reserve were conducted. Youth were also asked to suggest policies and programs that might lessen their stress. Upon completion of the study, we returned the findings to the

Youth Advisory Group for feedback and discussion.

Interviews were also held with youth-serving counselors and health workers about their perceptions of young Mi'kmaq women's stress experiences, as well as about policies and programs that they felt might assist female youth.

Findings

In the focus groups the young Mi'kmaq women talked about stress primarily as an *internal* emotional response. For example, being emotionally on-edge was mentioned 13 times (including irritability, frustration, anxiety), feeling down or sad was given 11 mentions, and feeling angry, 9. The women said they found stress relief by communicating their feelings with others. We observed the ease of communication among focus group women, with one group even claiming that the data collection exercise was therapeutic in itself.

In individual interviews, however, young women spoke of stress in *externalizing* terms, such as expressing anger or frustration (17 and 13 mentions respectively), and acting-out behaviours that included self-harm (12 mentions). Self-harm is usually considered a male phenomenon. This raises the alert that women may be at risk for self-harm.

The young women, in contrast to the young men and the reports of youth-serving professionals, cited a broad array of stressors. The fact that young women on reserve are experiencing multiple stressors must be considered in any overall framework of stress amelioration. One telling comment was that young men did not have "constant stress," implying that the young women did.

There was considerable overlap in key stressors named by respondents across the three groups; the Youth Advisory Group also concurred with this list. All three groups recognized family problems (e.g., an absent parent, drugs or alcohol) as an important source of stress. Young women rated school stress higher than did young men. Both groups of young people named relationship issues with their friends, including boyfriends/girlfriends, as a considerable source of stress. Violence and abuse were mentioned only by young women, and drug and alcohol use only by young men.

One of the unexpected positive results of this study is that both male and female youth described their identity as Mi'kmaq and spoke of their background with considerable pride. This positive identity is a remarkable and precious advantage for this group of on-reserve youth and should be preserved and capitalized upon for building successful life pathways as they move towards adulthood. In contrast, several youth-serving professionals cited lack of identity as an intra-personal stress.

Impressions of reserve life by gender revealed quite rigid role definitions for men and women. Young men also gave the impression that they were less likely to be forgiven for their mistakes (rowdy behaviour, for example) than were young women, for whom pregnancy (often regarded as a mistake by youth and adults) was commonplace. Both groups agreed that economic factors, such as women as the main breadwinner, could overrule male gender dominance. Both groups also recognized that women were considered responsible for the family. Some youth-serving professionals said that girls talked about the pressure to take care of other children in the family.

■ Both male and female Mi'kmaq youth described their identity as Mi'kmaq and spoke of their background with pride. This remarkable and precious advantage should be capitalized upon.

School is a major stressor of young people and there was consistency among the respondent groups about the reasons for a young person leaving school. For young men, it was often because of difficulty doing schoolwork, for which they blamed themselves, and for young women, it was often pregnancy. Most focus group females qualified this response by adding that the young mothers had no child care, which made leaving school the only option. Pregnancy was unquestioned as an interrupter for female Mi'kmaq students. Youth-serving professionals thought pregnancy among teen women was inevitable and did not distinguish between planned, unplanned, wanted, and unwanted pregnancies.

Policy and Program Interventions

All groups we met with called for more culturally-relevant education to help Mi'kmaq female youth reduce stress, recover from stressful experiences, and generally improve their lives. An improved school environment—described as

one with less racism, less bullying, and more sensitive teachers—might also be achieved through on-reserve schools. Counseling and learning supports were also deemed necessary. Only the young women mentioned the need for young mothers to have access to babysitting in order to remain in school. Starting school at 10 a.m. might be considered as a strategy for school retention given the late night lifestyle of youth, and the universal sleep disturbances of youth.⁹ The Youth Advisory Group concurred with a late starting time for school, and stated that Mi'kmaq, not French, should be the second language taught in school.

Most proposals were gender-neutral and very few young people commented upon jobs or educational supports. While few long-term socio-economic strategies were suggested, or strategies that addressed the broad determinants of health, the research team also recommends these approaches.

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Violence and Self-Harm Among Women in Conflict with the Law

Cathy Fillmore, Colleen Anne Dell, Elizabeth Fry Society of Manitoba, funded by the Prairie Women's Health Centre of Excellence

There has been an alarming increase in the number of women in conflict with the law who harm themselves. A 1995 study found that a full 59% of women in Canada who were sentenced for federal offences have self-injured.¹ In our 2000 study, *Prairie Women, Violence and Self-Harm*, we examined the connections among women who self-harm, critical events in the women's childhood and adult lives that preceded self-harm, and the women's position in the broader social structure. Although it is widely recognized that there is a link between childhood experiences of abuse and violence and self-harm, the linkages among self-harm, adult experiences of violence and abuse, and social position are frequently overlooked in the research literature.²

Our study found that adult experiences of violence and abuse—particularly partner abuse—were common among the women. An important finding is that some women linked abuse by their partners to self-harming behaviours and identified this abuse as a risk factor. Most of the women also shared a history of having grown up in highly unstable and unsupportive families and of being impoverished, both materially and socially. Another key finding of this study is that both Aboriginal and non-Aboriginal women said they benefited from and highly valued traditions from Aboriginal culture and said that these teachings should be incorporated into programs to address self-harm.

Data Sources

We interviewed 46 women with a history of being in conflict with the law, some of whom lived in the community and some of whom lived in correctional institutions. Aboriginal women made up 64% of the sample. (The remaining women identified as Caucasian (32%) and other (3%.) We conducted a focus group with six incarcerated women. We also interviewed nine staff members in community and correctional agencies. In addition to a survey of correctional

staff, we reviewed several community service and correctional institution policies and practices on self-harm.

For the data analysis, the narratives of the women in the community and in correctional institutions were combined because all of the women had a history of having been in conflict with the law, with the majority having experienced incarceration. Information gathered from community and correctional staff members was combined due to the limited number of staff respondents and the overriding similarity in responses between the two groups.

■ An important finding is that some women linked abuse by their partners to self-harming behaviours.

Based on the women's narratives, staff accounts, and a review of the interdisciplinary literature, we defined self-harm in this study as: Any behaviour, be it physical, emotional, social, or spiritual that a woman commits with the intention to cause herself harm. Self-harm is a means of coping with and surviving emotional pain and distress that is rooted in traumatic childhood and adult experiences of abuse and violence.

■ Women's self-harm cannot be abstracted from social contexts and structures.

Research Findings

In general we found that our respondents mirrored the profile of the female in conflict with the law in the Prairie region of Canada.³ The average age of the women was 31 years with a common educational level of grade 10. Most had relied upon social assistance at some point in their lives. Many of the women had been placed in various group and foster homes as youths. Most women revealed highly unstable and transient relationship patterns. The women had an average of two children, with the majority of the children in foster care, group homes, or adopted out.

The greatest likelihood of self-harm occurred when the women were in highly unstable and unsupportive families and adult partnerships. Such families were characterized by: frequent moving and intermittent or permanent placements in foster and group homes; absent, weak, or traumatic bonds with primary caregivers (especially the mother); unmet emotional and social needs; and childhood abuse and violence (sexual, emotional, physical, and neglect). In the women's adult relationships, abuse and violence, primarily by a partner, were common experiences.

Women in the community identified partner abuse, loss of and separation from their children, isolation, and loneliness as leading risk factors for self-harm. Similar risk factors were identified by incarcerated women, but with a stronger emphasis placed on traumatic recollections of past child abuse as a critical risk factor that was activated in prison.

The role of partner abuse has not been widely recognized in the research literature or in institutional and community responses to women's self-harm. Yet all of the women in this study (with one exception) had experienced violence and abuse as an adult, primarily by a partner. "With your spouse, you're too scared [to fight back] sometimes," one woman

said. "You've been hurt so many times, why not hurt yourself? 'There, I did it, you happy?'" The relationship between women's self-harm and partner violence is an important area requiring further investigation.

The women mentioned several functions of self-harm that enabled them to survive and cope with their unbearable feelings of emotional pain and distress. These functions included self-harm as a way of managing an abusive partner. However, several other important functions were identified: a need for attention and nurturing; self-punishment and self-blame; dealing with isolation and loneliness; distracting and deflecting emotional pain; release and cleansing of emotional pain; an opportunity to feel or bring oneself back to reality; an expression or communication of painful life experiences; and an act of control or power over oneself.

Most of the functions of self-harm identified by the staff in community and correctional agencies corresponded quite closely with those specified by the women. There were two main differences that should be noted. Staff minimized the importance of some of the functions identified by the women, such as to meet needs for attention and nurturing and as a response to isolation and loneliness. Another major difference was in the staff's interpretation of the women's self-harm as a form of manipulation and a way of getting staff to take control over them.

The women expressed a need for more opportunities to talk about and express their emotional pain and distress. In particular, they wanted greater recognition of their experiences of abuse and violence, both in the form of specific programs and in staff interactions. The women also felt a strong need to develop greater understanding and insight into their self-harming behaviours and to learn healthier and more empowering coping mechanisms.

The women said that Aboriginal approaches to healing were helpful and felt that these would be an effective component of programming on self-harm. This view was shared by the staff. Traditional Aboriginal programs were generally seen as offering a balanced and meaningful approach to self-recovery for women.

The women also emphasized that a harm reduction and protection planning approach was a more realistic and helpful response to self-harm. Their view was that many of the current practices to prevent self-harm are inappropriate. Research, in fact, has found that women are more likely to self-harm when preventative measures such as segregation are enforced.⁴ Punitive responses, such as restraints and segregation, may also re-traumatize women who have suffered experiences of childhood and adult violence.

It is important to note that the women in this study also demonstrated personal agency and a creative capacity for identifying alternatives to self-harming behaviour. The women wrote in journals and engaged in vigorous physical activity. Daily smudging (burning sage as a cleansing ritual) was used to attend to spiritual needs. The women also turned to friends and partners, sought individual counseling, group therapy, community programming, and community agency support. Volunteering, babysitting, and

other activities in which the women felt they were making a contribution were other resourceful responses.

Clearly, a holistic, woman-centered approach in policies and practices on self-harm is needed. This requires an account not only of women's unique personal histories and biographies, but also an understanding of the social antecedents of self-harm that are rooted in child and adult experiences of violence and abuse. Most importantly, women's self-harm cannot be abstracted from the social contexts and structures in which they live.

Following this study the Elizabeth Fry Society of Manitoba developed a brochure that suggests coping behaviors for women who are thinking of harming themselves. See below for contact information.⁵ A copy of the full report, *Prairie Women, Violence and Self-Harm* (2000), may be downloaded at www.pwhce.ca/pdf/self-harm.pdf or to order a copy contact:



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5. Contact: Elizabeth Fry Society of Manitoba, 773 Selkirk Avenue, Winnipeg, MB R2W 2N5, Tel: (204) 589-7335, Fax: (204) 589-7338.

The True Name of Her Condition

This article contains highlights from a study by the Immigrant, Refugee and Visible Minority Women of Saskatchewan, Inc., which was funded by the Prairie Women's Health Centre of Excellence.

The traumatized person is often relieved simply to learn the true name of her condition. By ascertaining her diagnosis, she begins the process of mastery.

~ Judith Lewis Herman¹

Between 1991 and 1996, over 4,000 women immigrated to Saskatchewan.² Among these were women from war-torn countries or countries where there has been high risk of exposure to incidents of extreme trauma, sexual violence, and disasters such as earthquakes, floods, and droughts. In themselves these experiences could produce a syndrome known as Post Traumatic Stress Disorder (PTSD), but research has shown that, in addition, the process of migration and the experience of settling in Canada adds to the distress and trauma.³ Our study of Post Traumatic Stress Disorder illuminates some of the barriers that immigrant, refugee, and visible minority women in Saskatchewan face in self-identifying or receiving a diagnosis of PTSD and healing from it.⁴

Most significantly we found that a complex set of barriers prevented the identification of PTSD in the women who suffered from it. A lack of sufficient training in the English language and a lack of knowledge about PTSD meant that most of the 20 women in the study group did not know “the true name of her condition.” Some women reported an exacerbation of symptoms as a result of experiences of racial discrimination, professional decertification, and other consequences of settlement in Canada. Of the women who had sought help from physicians, some reported encounters in which their symptoms were ignored or trivialized. While there appeared to be strong theoretical knowledge of PTSD among the one general practitioner and four psychiatrists we interviewed, they reported that they had worked with few immigrant or refugee women in the province.

Because one objective of the research was to gather information about the experiences of Aboriginal women with

PTSD in order to recognize parallels with immigrant and refugee women and build partnerships, we also interviewed Aboriginal women. Only two, however, participated in our study. It was through our interviews with mental health professionals and service providers that we learned that there are strong links between Aboriginal, immigrant, and refugee women and PTSD. This finding warrants further research.

What is PTSD?

Before a diagnosis of PTSD is given by a psychiatrist or psychologist (based on the description in the *Diagnostic and Statistical Manual of Mental Disorders* (DSM)), sufferers must display at least one of the following symptoms:⁵

- recurrent and intrusive distressing recollections of the event;
- recurrent distressing dreams;
- dissociative episodes (flashbacks);
- intense psychological distress at exposure to events that symbolize or resemble the traumatic event.

It's important to note that PTSD is not the equivalent of being mentally ill. “The problem does not originate within the individual's personality, but rather that an external event has created lasting, but not incurable, symptoms or reactions.”⁶

Those who seek treatment for PTSD are often misdiagnosed. Therapists may focus on presenting problems such as eating disorders, depression, and substance use.

Research Findings

While PTSD may have a devastating impact on the lives of sufferers, many avoid treatment. The immigrant and refugee women in our study confirmed this. They reported that, within their countries of origin and cultural communities,

there is a stigma associated with sexual violence that silences sufferers. There is also a stigma associated with having mental health problems and using services for such problems.

Of the twenty women who participated in our study, only five had been diagnosed with PTSD by a professional. These women, and others who found out about PTSD in other ways, described the relief they felt upon learning about the syndrome. "A liberating experience," is how one woman described it. Another said, "Actually, I thought I was going crazy...when I started going to this counselor she gave me a book to read...that helped me." Knowledge about PTSD played a major role in the women's healing journeys. But it was only the women who had the most well-developed English language skills who were able to use media and services that provided them with the information they needed. This point was raised by virtually everyone we interviewed in the study: the lack of ability to communicate in English poses a significant obstacle to immigrant and refugee women's abilities to identify and address their problems.

The women described diverse traumatic events and symptoms of PTSD. Witnessing violence, torture, disaster, or living in situations of extreme violence were common. Experiences of PTSD included fear, panic attacks, nightmares, memory loss, flashbacks, sadness, loneliness, depression, and suicidal ideation. Three women also expressed fear for their children who had been traumatized by war and by the process of migration and settlement. One woman described her eleven-year-old daughter, "Every night. She's still dreaming about Kosovo, how the war it was in Kosovo."

For some women, symptoms of trauma became enmeshed with the day-to-day struggle of adapting to a new

environment, often without language skills, community, or family support. Four women described experiences of racism and discrimination in Canada. One woman had lost her job because of her language skills, another related that people teased her about how she spoke, and another said she had suffered verbal abuse, including "racial comment." Some women could not find work because their professional certifications were not recognized in Canada. For them living in Saskatchewan meant a loss of status, job, and career.

Of the women who had sought help, four noted that their physicians were not helpful. "I read something about this doctor," one woman recounted. "So I went to see him and said—you know it was like an act of desperation—like 'I am not doing well. I just want to see what you can do for me.'...And he looked at me and said..., 'Well, I can't understand why you haven't gotten over this...you should see people from El Salvador coming here. They were mutilated and everything.'...I was devastated because that increased my feeling of guilt and ...those were the feelings I had to deal with the most, you know, the guilt of having to survive."

More positive experiences resulted from contact with service providers in community-based organizations. In particular, women who used those services were appreciative when there were drop-in programs with other immigrant and refugee women. Knowing other women shared their response to traumatic events was greatly comforting.

The psychiatrists we interviewed expressed a strong empathy and openness to working with the immigrant population, but they had little opportunity to do so because few members of that population attend mental health services. Service providers also stressed that they were learning much

■ A complex set of barriers prevented the identification of PTSD in the women who suffered from it.

■ “[The doctor] looked at me and said, ‘Well, I can’t understand why you haven’t gotten over this...you should see people from El Salvador coming here.’”

about PTSD from their interaction with Aboriginal women. They described the large numbers of Aboriginal women they were seeing who had been subject to, as one psychiatric nurse noted, “a lifetime” of “all types of abuse.” They suggested that this learning might be useful when addressing similar issues with immigrant and refugee women.

Recovery from PTSD will be facilitated when health services, and programs aimed at serving immigrant and refugee women, integrate awareness of PTSD into their staff training and service programs. We also recommend that adequate funding be allocated for ESL programs for immigrant and refugee people coming to Saskatchewan. Finally, further research is needed to discover the links and differences between immigrant and refugee and Aboriginal women who

suffer from PTSD in order to develop partnerships, programs, and services that best suit their needs.

A copy of the full report, *Post Traumatic Stress Disorder: The Lived Experience of Immigrant, Refugee and Visible Minority Women* (2001), may be downloaded at www.pwhce.ca/research.htm#immig or to order a copy contact:



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Queer Women's Health Research: Methodological Questions

Jacquelyne Luce, Social Science and Humanities Research Council Postdoctoral Researcher, Institute for Women's Studies and Department of Sociology, Lancaster University, Lancaster, England, British Columbia Centre of Excellence for Women's Health¹

During the late 1990s images of pregnant and parenting lesbian/bi/queer² women appeared increasingly in news stories, advice columns, comic strips, television sitcoms, and feature films. Yet, as a graduate student in anthropology with a passion for reproductive health research and as a queer wanna-be parent, I wondered about lesbian/bi/queer women's experiences of trying to get pregnant and/or trying to become parents. Between March 1999 and October 2000, I conducted ethnographic fieldwork, primarily in British Columbia, on lesbian/bi/queer women's experiences of trying to get pregnant or become parents over the past twenty years. I participated in events and activities within queer and health service "communities" that were related to reproductive health, parenting, and same-sex rights legislation. Travelling to various cities, towns, and rural regions of British Columbia, I interviewed 80 lesbian/bi/queer women about their experiences of choosing donors, mail-ordering sperm from American sperm banks, using fertility drugs, experiencing miscarriages, getting pregnant, and having difficulties conceiving. Some of my experiences and findings based on research I conducted in smaller communities were published in *Making Choices/Taking Chances: Lesbian/Bi/Queer Women, Assisted Conception and Reproductive Health* (2002). In that report I integrated some of my fieldwork reflections with the stories

of women I interviewed. Here I revisit three of the narratives originally published in that report to explore some of the methodological questions that were raised in the process of doing queer women's health research.

March 1999, Vancouver: The taxi driver picked me up outside of my apartment building on Commercial Drive. I was on my way to Prince George to begin my fieldwork. As we drove up Commercial and then Victoria Street, the driver commented on the change in the neighbourhood. "It used to be," he said, "that you wouldn't be caught in this area unless you were a screaming faggot."

A significant body of research on "lesbian health" has emerged over the past two decades. Most of this research focuses on lesbians' encounters with health professionals in institutional health care settings and consistently identifies homophobia, heterosexism, and invisibility as barriers to lesbians' access to health care.³ In my study I was interested in exploring lesbian/bi/queer women's experiences of assisted conception and reproductive health in the context of everyday life. How did women negotiate the meanings of health, choices about donors, and perceptions of risk in relation to their experiences as lesbian/bi/queer women living in large urban centres, small rural communities, and

■ I was surprised by the absence of researchers' experiences of homophobia in written reports. Yet I found myself bracketing off various encounters and refusing those experiences entry into the frame of my analysis.

■ “Being in the field is more a matter of looking and listening in particular anthropological ways, rather than being in particular kinds of places.”

northern cities? The process of doing this research raised new methodological questions for me about the meaning of constructing boundaries between personal and professional experiences. Writing about doing research on midwifery in Ontario, Margaret MacDonald reflects, “Being in the field is more a matter of looking and listening in particular anthropological ways, rather than being in particular kinds of places.”⁴ Anthropology, then, is a perspective, a lens through which to view the world. One’s fieldsite can become everywhere, everything. However, it was through the practice of focusing an anthropological and ethnographic lens on everything that I realized there were experiences that I didn’t want to deal with and didn’t want to analyze. Prior to beginning my fieldwork, I was surprised by the absence of researchers’ experiences of homophobia in written reports. Yet I found myself bracketing off various encounters, like the one with the taxi driver above, and refusing those experiences entry into the frame of my analysis.

September 1999. Pride Day, Prince George: *I’m holding Samantha’s one-year-old daughter. I see a number of people I recognize from my previous fieldtrip...Samantha looks around at the thin crowd. “I really hope more people come,” she says. “This can be really scary.”...The emptiness of the sidewalks startles me. Occasionally a few people stop to watch. A few people clap.*

In “Agendas for Lesbian Health,” Jennifer Terry reminds us of the energy it takes to make topics such as lesbian health issues our subjects of study.⁵ Her remarks emphasize the need for lesbian health researchers to recognize how encounters with homophobia and heterosexism in the stories of research participants, the everyday practices of

doing research, and our own daily lives, impact our own health and well being. When I initially arrived in Prince George, another anthropologist commented that perhaps research like ours begins the moment we step out the front door. Perhaps. As a researcher, it was much easier to talk about constructions of queerness and discrimination in relation to women I interviewed and by drawing on experiences that I shared with them. I could engage with discrimination against lesbian/bi/queer women through my re-telling of *their* stories. However, the experiences of homophobia and discrimination that I encountered over the course of my fieldwork were relegated to the periphery of my study and marginalized as “data.”

September 2000, Duncan: *A woman standing in front of a hair salon watches me tack a poster about my project onto the community bulletin board. I cross the street to see if she knows anyone who might like to share their story. Reading the poster, the woman nods. “I know a few people who might know someone.” “Great. Could you please pass on the flyer?” The woman shakes her head, “No. In my line of work I just can’t do that.” I know that I am supposed to nod in understanding. But I don’t.*

I wanted to interview women who accessed services but did not come out to providers, women who became pregnant by self-insemination or physician-assisted insemination, women who had had sex with men to get pregnant, and women who had not been able to conceive. In order to do so I needed to tell as many people as possible about my project. This often meant asking strangers for permission to post flyers about my study in public places such as grocery stores, libraries, dental practices, and cafés. It meant placing my posters next to those

advertising “Heterosexual Pride Day.” And, when people asked me “What do you do?”, I would tell them about my project. I often found myself answering “straight” people’s questions about lesbians and listening to homophobic perspectives on lesbian parents. Some people, like the woman above, implied they were unwilling to pass on the poster for their own protection, while many others expressed that they didn’t want to offend women they thought might be interested in doing an interview by passing on information about a project about lesbian/bi/queer women. In many ways lesbian health research is hindered by practices that maintain the so-called invisibility of lesbian/bi/queer women in the name of protection. My refusal to render lesbian/bi/queer women invisible in the poster information, descriptions about my research, and funding proposals became my way of countering the normative expectation that sexuality or sexual identification is a private matter.

Just as homophobia, heterosexism, and invisibility can obstruct lesbians’ access to health care, they can also inhibit research on queer women’s health issues. Women I interviewed employed numerous strategies to maintain their health in the face of everyday heteronormativity. My own strategic reframings of my research, and what counts as data, also provide a means of maintaining my own health. By reincorporating experiences such as those described above

within the frame of analysis, I hope to establish a basis for thinking through some of the methodological questions facing queer health researchers and for developing various initiatives to support research on lesbian, bisexual, and queer women’s health.

For a full account of this study see Luce, Jacquelyne. *Queer Conceptions: Lesbian/Bi/Queer Women, Assisted Reproduction and the Politics of Kinship* (unpublished doctoral dissertation), Department of Social Anthropology, York University, Toronto, 2002.

A copy of the report, *Making Choices/Taking Chances: Lesbian/Bi/Queer Women, Assisted Conception and Reproductive Health* (2002), may be downloaded at www.bccewh.bc.ca/Pages/pubspdflist2.htm or to order a copy contact:



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NOTES

1. This project was funded by the Gay and Lesbian Medical Association Lesbian Health Fund, the Agency for Healthcare Research and Quality (R03HS11266-01), the British Columbia Centre of Excellence for Women's Health, the Social Science and Humanities Research Council, and York University.
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STUDYING DIVERSITY IN THE COMMUNITY

Peer Research in the Sex Trade

How does public policy affect the health and safety of sex workers? Frances Shaver of Concordia University and Jacqueline Lewis and Eleanor Maticka-Tyndale of the University of Windsor secured funds from the Social Science and Humanities Research Council to study this question. With the support of the National Network on Environments and Women's Health, they held workshops and developed The Sex Trade Advocacy Research Workbook to train sex trade workers as research assistants for the study.

Frances Shaver spoke to Leslie Grant Timmins of the Research Bulletin.

In the short run, even in the long run, the status quo and the law on sex trade work are not going to change. We're not going to move into decriminalization, for example. In the meantime, given the state of law, what can we do to ensure the safety and well being of women and men and transgendered people involved in the sex trade? That's the focus of this study. We're interested in the extent to which people in the sex trade have access to health services, social services, retraining services, education—things that those of us who are less marginalized and stigmatized take for granted.

Sex trade workers are disenfranchised: they rarely have the benefits and protections available to other workers through labour legislation. In our study some of the questions focus on work issues. We're asking sex workers for recommendations about how they can make their work safer and what others might do to make it safer.

Our study population includes women and men and transgendered people who work as exotic dancers, escorts, and in the street trade. We're interested in exploring the diversity of jobs within the sex industry and in collecting data about the diversity of workers, rather than in reinforcing a single portrait. The stereotype is the street prostitute—the poor victimized woman or girl with a background of physical or sexual abuse, some kind of drug

dependency, and an abusive boyfriend or pimp. This profile represents only a small segment of the people I've met in the field. Unfortunately, good comparative data about these different groups or about the variety of forces that lead people into prostitution are hard to find. The data we're collecting now are designed to bring out similarities and differences that may exist in terms of access to services. Some sex workers are quite well established. They may own their own home and those who do certainly have access to health services. They're still subject to the same stigma about their work, however.

We hired and trained people who are, or have previously been, sex trade workers to recruit and interview respondents. We're working closely with our community partners, the Exotic Dancers' Alliance of Ontario, Stella Montreal, and Maggie's Toronto. Why did we take this approach? Because we felt it would enhance the quality of the data to be collected. Community partners provide a different perspective and it increases the synergy of ideas and resources when you work in close collaboration with them. We can also offer a choice to respondents: do you want to be interviewed by a sex worker or another member of the team? And particularly when researching the sex trade people say, "Well, who are you? You drop in here and disappear after asking these questions." By hiring and training sex trade

■ It enhances the data and increases the synergy of ideas when you work in close collaboration with community partners.

workers it allows us to give back to the community in a very real way, in terms of research experience, more understanding of how research operates, and employment.

There are always challenges in academic-community research partnerships, it doesn't just occur when working with sex trade workers. Time wise it's a very costly way to do research. You spend a lot of time with your partners building and maintaining trust. There are questions about things I might take for granted, such as what reporting means, the difference between lay and academic articles, confidentiality and anonymity. There are also ethical tensions about whether one can be both a subject and a researcher. Does the research assistant know the person they're interviewing? There's a risk involved in interviewing a friend in terms of getting accurate information. We address this in the training. Another concern arises when something goes wrong. I see it as exciting—at least intellectually—and think we learn as much from failure as from when things go well. But to community partners and student assistants, this can be threatening.

In Montreal we were able to find and train several research assistants from the industry to work with us. In Toronto, we were less successful. I'm not sure why. Perhaps because in Toronto many of the people who came to the workshop for training were also key activists within their community organizations. The majority of those who attended the Montreal workshop were not involved in the regular activities of the community organization they represented.

I'd like the community research assistants to be involved in data analysis, but there's very little money left to pay non-students. I want to involve them because they can help point out where we might be misinterpreting or concluding inappropriately. Even to the extent of pointing out that the language we use may type or marginalize the respondents. Their involvement may also create tensions—the data could reveal something different than their own personal experience has shown them. This provides for more synergy and becomes another part of our ongoing training. I do know that the sex workers we have hired and our contacts at our community partner, Stella, in Montreal will want to look at the data, contribute to its analysis, and provide input to the final reports.

From academic colleagues, but also in the media, when I'm presenting findings about sex trade workers there are other challenges. People call in to a radio show, for example, and say to you, "*They're* not going to tell you the truth. They're not going to be honest about their drugs, their illegal activities, their pimps." I always have to do enormous work to ensure that nobody can challenge the validity of the data. This is because facts are a poor eraser for the emotional baggage coupled with the stereotyped profile of "the prostitute" and are often the first aspect of the study to be challenged.

■ Community partnership is highly valued by funders but at the same time it's under-funded.

Would the manual for training research assistants be different if secretaries were the study group? Probably not. What has to be built into this project is acclimatizing people to this particular study environment. Acclimatizing the students who are working on the study, who have never been in a strip club and have to learn how to go in there and get permission from the owner or manager to put up recruitment posters. Acclimatizing to get rid of stereotypes about how one feels about people involved in the sex trade. The sex workers who come for training have to learn what research is about, what the budgets involve, how to negotiate within an unfamiliar academic environment. Both have to learn how to recruit participants and conduct interviews with a hidden population.

The subject matter and collaborative method bring up other issues. For example, the sex trade workers who are conducting the interviews already know all this stuff and so they tend not to probe for more information. Students don't

Beyond Inclusion

by Wanda Thomas Bernard

In women's health research, moving beyond inclusion means establishing research agendas that specifically deal with diversity and integrating an analysis of the impact of diversity on any particular issue under study. I use the term "diversity" to refer to the cultural, racial, and social differences that mark off the oppressed or marginalized: for example, poor people, Aboriginal people, people of colour, persons with disabilities, gay, lesbian, bisexual and transgendered people, and women. The term also refers to diversity within these groups. Understanding diversity means moving beyond awareness and analysis of the dynamics of oppression and marginalization, toward appropriate social change and social action.

Action means sharing individual and collective power in health research and health care and using power and privilege to effect change. It means a major paradigm shift in the way we think about diversity, moving from a position of "adding on" diversity to making diversity a central component of one's work.

Women's health researchers and advocates need to ask tough questions about their own organizations: What communities do they serve? Do agency programs, services, policies and procedures reflect this diversity? Who is and who is not sitting at the table with us, and what can we do to get those who are missing there?

Wanda Thomas Bernard is Director of the School of Social Work, Dalhousie University, and a member of the Black Women's Health Network. "Beyond Inclusion" can be read in its entirety in *Race, Ethnicity and Women's Health* (2002). For a copy, contact:



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probe either, but this is because they are shy or tend to feel it is disrespectful. So probing is a skill we continue to address in our ongoing training sessions.

It's exciting to be involved in a collaborative academic-community partnership, but it's also very, very time-consuming. Community partnership is highly valued by funders but at the same time it's under-funded. We need to educate stakeholders. We need to ensure there are monies to pay our community partners for their contribution. We need our institutions to recognize the practical work we do (write reports for lay people, for example). Currently we receive very modest kudos in the academic world for these reports and they don't count toward promotion. In addition, our community partners may ask us to help write a press release, or design a small survey, or write a letter to the editor, or respond to a government report, get involved with whatever they're doing to promote their concerns. These activities are essential. They add time to the research process, but rarely count in our institutions. Those involved in community-academic partnerships are developing a different kind of knowledge—we're both building our capacity—but we need appropriate funding and more realistic time frames if we are to continue to excel at this type of research.

This study will produce pamphlets in hard copy and on the Internet for sex workers about how to improve safety and health while working. It will also produce reports for policy makers and frontline organizations on how their organizations affect safety and health for sex workers and how this can be improved. To download or order a copy of *The Sex Trade Advocacy Research Workbook* go to www.yorku.ca/nnewh/.



National Network
on Environments and
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